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**Running head:** Experiences of exercise in people with MS

**A qualitative investigation of exercise perceptions and experiences in people with multiple sclerosis before, during and after participation in a personally-tailored exercise program**

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ACCEPTED MANUSCRIPT

**A qualitative investigation of exercise perceptions and experiences in people with multiple sclerosis before, during and after participation in a personally-tailored exercise program**

**ABSTRACT**

**Objective:** To undertake a qualitative investigation of exercise perceptions and experiences in people with MS (PwMS) before, during and after participation in a personally-tailored program designed to promote long-term maintenance of self-directed exercise. **Design:** Focus groups and semi-structured telephone interviews. **Setting:** University Exercise Science Department close to the recruiting hospital. **Participants:** PwMS (N=33; aged  $47.6 \pm 7.9$  y). **Interventions:** Participants were recruited after participation in a randomized controlled exercise trial; all had been allocated to a 12-week exercise programme, comprising supervised and self-directed exercise sessions. **Main outcome measure:** Exercise perceptions and experiences before, during and after participation in the program. **Results:** Four themes emerged from the analysis: (1) the transition to inactivity; (2) lack of knowledge and confidence; (3) positive exercise experiences; (4) perspectives on exercise adherence. **Conclusion:** Lack of confidence and exercise knowledge, coupled with negative perceptions about physical capabilities after an MS diagnosis, are clear barriers to exercise participation in PwMS. These issues are not being adequately addressed as part of the healthcare pathway or in community settings. Perceptions of improved posture, ability to overcome everyday difficulties, acute mood enhancements during and after exercise and increased opportunities for social interaction were amongst the reported benefits of exercise participation. Despite the provision of a personally-tailored exercise plan and use of cognitive behavioural strategies, self-directed exercise continued to present challenges to PwMS and the importance of seeking cost-effective ways to maintain motivational support was implicit in participant responses.

**Keywords:** Multiple sclerosis, exercise, qualitative evaluation

## INTRODUCTION

Studies have shown that exercise is a safe non-pharmacological treatment strategy for people with multiple sclerosis (PwMS), with the reported health benefits including improvements in muscle power, physical and psychological functioning, fatigue and health-related quality of life.<sup>1</sup> However, following an MS diagnosis, perceived functional limitations, safety concerns and loss of confidence, fatigue, lack of MS-specific exercise knowledge or conflicting advice from health professionals and accessibility issues associated with inadequate transport, physical environment and social factors (e.g. social obligations, lack of social support) become important barriers to exercise participation.<sup>2-3</sup> Cross-sectional evidence suggests that only ~20% of PwMS are achieving recommended amounts of daily moderate to vigorous intensity physical activity<sup>11</sup> and strategies to address common barriers are needed to increase the level of engagement.

Confidence in managing disease-specific symptoms, as well as positive coping styles, self-regulation skills and engagement with social support structures are salient personal characteristics of PwMS who continue to be physically active after diagnosis.<sup>9, 12</sup> In addition, the support and knowledge gained from competent health professionals, perceived physical, mental and social benefits, peer support and camaraderie during group exercise, and feelings of accomplishment, self-management and control are important facilitators that lead to improved self-efficacy for exercise.<sup>4, 6-8, 13, 14</sup> Despite this, Kayes et al<sup>10</sup> concluded that the decision to engage in physical activity is complex, individual and fluid amongst PwMS, reflecting the day-to-day uncertainty of the condition. This suggests a personalised approach to barrier management may be needed. Furthermore, programs which provide support for self-directed exercise, taking into consideration the day-to-day challenges MS symptom management, individual capabilities and personal preferences may be more effective for promoting sustainable physical activity behaviour change.

We recently reported on health and cost utility outcomes following a randomized controlled trial which investigated a pragmatic approach to developing the skills and confidence for long-term maintenance of self-directed exercise in people with mild to moderate MS (ExIMS).<sup>15 16</sup> The program provided access to an exercise physiologist and physical therapist, who applied cognitive behavioural techniques during a graded decrease in the frequency of individually-tailored supervised exercise (three exercise sessions per week for 12 weeks, with the ratio of supervised to home-exercise sessions being 2:1 in weeks 1-6 and 1:2 in weeks 7-12). There was high adherence to supervised and home-based exercise (>80%), accompanied by improvements in fatigue and quality of life after 12 weeks, and a sustained improvement in quality of life 6 months after withdrawal of supervision.<sup>15</sup>

The purpose of this study was to undertake a qualitative investigation of exercise perceptions and experiences in people with MS (PwMS) before, during and after participation in this personally-tailored program designed to promote long-term maintenance of self-directed exercise. An improved understanding of exercise perspectives and personal experiences of engaging with programs that can develop skills to support the self-management of MS will inform future healthcare implementation strategies aimed at enhancing patient care.

## **METHODS**

### **Study design**

We used qualitative research methods to explore exercise perceptions and experiences. Our underlying philosophy was constructivist,<sup>17</sup> recognising the individual nature of experience and the impact of people's wider life experiences on their perspectives of exercise both before and during the trial. Data collection used both focus groups and individual interviews. An advantage of focus groups is that social interaction between group members can increase the depth of

inquiry, stimulating discussion of shared experiences and their meaning to each individual.

Conversely, interview responses can provide participants with more opportunity to contribute so using a combination of methods can yield different viewpoints.<sup>13</sup> In addition, we were keen to understand all participants' experiences; and offering a choice of methods meant that participants unable to join focus groups could organise interviews around their availability.

## Participants

A purposive convenience sample of 54 PwMS who had participated in the 12 week exercise program<sup>15</sup> were invited to take part in the qualitative investigation. Of these, 33 participants agreed to participate and were recruited within 6 months of completing the program and their characteristics are presented in Table 1. Written informed consent was obtained prior to study participation and ethical approval was granted from NHS South Yorkshire Research Ethics Committee.

## Focus groups and telephone interviews

A total of 29 participants took part in the focus groups and four participants were interviewed by telephone. Six focus groups (2-8 participants; 60-80 min duration) were facilitated by two researchers trained in qualitative research techniques. Facilitators were not directly involved in the exercise trial but do work in exercise research. Telephone interviews (~30 min duration) were conducted by a member of the trial team who had delivered some of the exercise training sessions. All participants were briefed about the purpose of the discussion, i.e. to elicit their views and experiences of exercise and engaging in the program, and the same semi-structured *a-priori* topic guide consisting of open-ended questions was used flexibly to guide the focus group and interview discussions (Table 2). Focus group discussions and telephone interviews were audio-taped and then transcribed verbatim by a source independent of the study. Participant anonymity was assured by the assignment of reference numbers.



## Thematic framework analysis

Using framework analysis,<sup>18</sup> HC and LH independently read and re-read the transcripts several times to become familiar with the data, before coding, indexing and charting to create an initial key thematic framework with sub-themes. Analysis aimed at describing the individual's experience of exercise, searching for common, recurrent patterns but also identifying insights into participant experiences that might explain behaviour and improve advice and services in the future. NS and AC read the transcripts and independently applied the coding framework. The coding framework represented all relevant data and there was a high level of agreement between analysers. This approach to data analysis is somewhat deductive, framing the analysis within an *a-priori* topic guide, yet the data were borne out of original transcripts from focus groups and interviews.<sup>19</sup> Data saturation was achieved, in that similar themes arose repeatedly and no new themes arose in the final focus group or interview.

## RESULTS

The findings are presented under four key themes, which contextualise the experiences of participants in the study. Direct quotes, with reference to either focus group and participant number, or telephone interview and participant number, are presented to illustrate the key themes and sub themes.

### *Theme 1: The transition to inactivity*

Prior to MS, many participants had valued the personal, social and health benefits of a physically active lifestyle, however, their MS diagnosis caused a transition into physical inactivity. Several participants recounted how regular exercise was a part of 'normal life' before MS and helped to define their self-identity. Comments included: "*I used to play a lot of sport. So I was pretty active*" (FG1:3) and "*I was a gymnast...did loads of exercise, running*" (FG3:1).

For others, an active lifestyle before MS had been a shared and valued experience with family and friends, a social activity or something that was done for fitness, recreation and health: *“I became like one of those people who use the swimming pool, jacuzzi, sauna and things like that on a Sunday morning”* (FG1:1).

However, a diagnosis of MS had created a transition toward physical inactivity and a perceived reduction in exercise capacity for many participants: *“I would say I became very inactive”* (FG1:2). Other participants attempted to maintain their exercise levels but found it difficult: *“I was still a member of a gym but it ended up that I would drive to the gym and then I would be sat in tears in the car thinking I can't do that... so I gave up going to the gym because it is supposed to be there to help me but it was carving me up and making my symptoms worse”* (FG1:4). A small minority of participants were able to maintain regular exercise by becoming adept at pre-empting situations, planning ahead and making adaptations to their lifestyle with a positive frame of mind.

## *Theme 2: Lack of knowledge and confidence*

There was general consensus that exercise advice from health professionals was either non-existent or not relevant for the needs of PwMS. Participants recalled that exercise and lifestyle advice was not generally offered after their MS diagnosis: *“I don't recall any professionals mentioning anything about exercise at all and I don't believe I asked”* (FG5:2). Participants felt that endorsement from the clinical team was needed to confirm that exercise was something you were allowed to and supposed to do, but this advice was variable: *“When I was diagnosed I asked specifically if there was anything I could do to help myself, diet wise and exercise and I was told there was nothing you could do whatsoever”* (FG2:6). Other participants were referred to local facilities but the tailored exercise advice and support they needed was lacking: *“My physiotherapist referred me to the local sports centre and then a gentleman was trying to make*

me a plan of what to do, and he hadn't dealt with anybody with MS before and actually it was a bit of a disaster... (FG3:1).

Building a rapport with knowledgeable exercise specialists who were able to adapt exercises to take account of physical limitations and provide knowledge about safe and effective activities and appropriate progression was important: "... this was an opportunity for me to come to someone, a bit like a personal trainer really, who would know me, get to know me and teach me how to do it. Which is exactly what I got. For me that's what kept me coming..." (FG5:2).

Participants felt that the exercise specialists taught them how to recognise signs that they are doing too much and how to pace themselves: "You are scared because you immediately get the symptoms from the increased body temperature and everything anyway, my feet automatically have pins and needles all up my legs and that is murder and it is a sign that I will have to stop and in actual fact what I have learnt is that it will fade, that is alright, it is your body just reacting and increasing temperature and is perfectly normal and carry on" (FG6:5). Participants described a shift in their perceptions by learning that they do not need to exercise to exhaustion to experience health benefits, and that they could progress slowly, at their own pace: "Whereas I wanted to run she was still teaching me to walk, so from that point of view I learnt a huge amount and gained a huge amount and that's how I am taking it forward. Not pushing it to the limits where I'm dropping, but building it up very slowly" (FG5:20) and "... you think I can't possibly do that and it just seems a huge obstacle but actually now knowing that you can do a few minutes or a minute even at times and it will count, so it is achievable and attainable isn't it?" (FG6:2). Another participant said: "For me, I think it was taking the mystery out of exercise and giving the confidence that it's safe to do this and you'll get benefit from it... and I think guided exercise in the initial stages was the key" (T3).

Theme 3: Positive exercise experiences

There were new insights in to the positive physical, mental and psychosocial experiences that engaging in an exercise program can bring. The majority of participants were grateful to have had the opportunity to take part in a tailored supervised exercise program; they recounted: "... I was looking forward to it every week, it gives you a regime to work to" (FG1:1) and "I just really enjoyed it and found it really rewarding" (FG6:2). In some cases, having a reason to leave the house was a valued benefit of taking part in the program: "I really enjoyed the social aspect of meeting people and talking because you don't always get that when you have MS. You tend to be at home a lot on your own so I enjoyed coming..." (FG6:3). For others, improved health and fitness created new opportunities to engage in recreational activities with their families: "I try harder. My little boy will be surprised when I say yeah, alright I'll go swimming or yeah OK let's go for a walk, and he'll think Oh, that doesn't sound quite right" (FG4:4).

There were perceived improvements in physical fitness: Comments included: "...I think I felt generally stronger" (T2) and "I know for me, I felt I was a lot straighter, standing straighter" (FG1:2). Daily physical functioning was also improved: "I do find simple things like turning over in bed, which isn't a very easy task, and picking things up off the floor without collapsing; things of that nature are a lot easier" (T1) and there were reduced feelings of fatigue: "I feel as though I'm less fatigued. I don't have as many floppy days. I still get the odd one but nowhere near like it was" (FG4:7). The acute health benefits of participating in the exercise sessions were also reported, including mood enhancement and a sense of wellbeing and achievement. One participant recounted: "I always feel better having done the exercise" (FG1:4) and others spoke of: "A good sense of wellbeing and you'd achieved something" (FG3:1) and "...an adrenaline buzz, whilst you're doing it, so you feel that you've achieved something..." (FG3:4). One participant reported finding the exercises difficult and at times experiencing some pain but

was still able to complete the program, achieving a volume of exercise that was manageable for her.

#### *Theme 4: Perspectives on exercise adherence*

Participants universally agreed that maintaining self-directed exercise at home was more challenging than attending supervised sessions. Regarding adherence to the supervised sessions, one participant said: “...*I am the kind of person that will stick to an arrangement I've made. I will stick to a commitment*” (FG6:1). However, finding personal motivation to exercise and having insufficient self-control to put their exercise intentions into action were barriers to staying active at home: “*I've found that because you have no structure once you are at home you do tend to sit around and watch a bit more TV rather than when you have to come [to the centre]... when you're at home, you think I'll not bother today*” (FG6:3) and “*I've had the incentive to come, and I've enjoyed coming, doing it at home and now it's finished I've just gone back to how it was before*” (FG1.1).

For some, enjoyment of participating in exercise enhanced their motivation: “*I've tried to keep the willpower in my head... and it's working because I do enjoy it*” (T4). For others, the rationale for doing exercise at home was promoted by feelings of guilt: “*Being at home I must admit I got a bit of a guilty feeling knowing that I was supposed to be doing another two physical activities and thinking you can't just sit there, you've got to go out and do something. There was a guilt thing that made me do the home [exercise], which I did, but also my husband who was saying "don't you think you should be doing..." I got pressure from him which was good but I think for enjoyment I much preferred [attending the centre] for the structured [exercise]*” (FG5:1).

## DISCUSSION

This qualitative study provides new insights into the exercise perspectives and experiences of PwMS before, during and after participation in a program that was designed to develop the confidence and skills for self-directed exercise. Following their MS diagnosis, many participants experienced a loss of confidence in relation to their perceived physical capabilities and lack knowledge of how to safely engage in exercise (Theme 1). Fear of exacerbating MS symptoms and/or making the condition worse has previously been identified as a barrier to exercise in PwMS<sup>6, 10, 20</sup> and is compounded by a lack of MS-specific exercise advice (or conflicting advice) following diagnosis (Theme 2).<sup>4, 8, 21, 22</sup> Our results reaffirm the need for confidence building and MS-specific exercise advice following diagnosis.

In accordance with previous studies,<sup>6, 7, 13</sup> participants felt that the supervised component of the program, and particularly having access to competent health professionals (exercise physiologist and physical therapist), was important for developing confidence to exercise via an improved awareness of their physical capabilities (Theme 2). Fatigue has been identified as an important barrier to exercise in PwMS,<sup>10, 21, 23</sup> and the importance of learning how to properly pace themselves during exercise to avoid fatigue was valued, as was expert advice to progress slowly, even if some found this frustrating. Through this reassurance, some participants learned not to be afraid of the neurological sensations induced by exercise. Indeed, many experienced significant health benefits from what they felt was a surprisingly low but manageable level of physical activity. The average amount of weekly moderate intensity aerobic exercise achieved by participants was ~68 minutes,<sup>15</sup> representing only ~45% of current recommendations.<sup>24</sup>

The reported improvements in physical functioning and perceptions of MS fatigue were consistent with previous reports,<sup>3, 22, 25</sup> but there were some new insights into how exercise can improve everyday posture and daily functioning, from being able to stand more erect to an

enhanced ability to reach down for things on the floor (Theme 3). The positive shift in perceived physical health and mental outlook also created new opportunities to enjoy more recreational physical activity time with their families. Acute mood enhancements and a sense of accomplishment during and after each exercise session were also experienced, as in previous studies.<sup>14, 21</sup> Other participants placed great value on the opportunity for social interaction that was presented by engaging in the exercise program, consistent with the findings of Learmonth et al.,<sup>26</sup> especially where their MS had led to greater social isolation. These new insights highlight the value of qualitative investigations in identifying health and psychosocial benefits associated with exercise that are valued by PwMS.

Participants universally agreed that maintaining self-directed exercise during and after the 12-week program was challenging, despite their positive experiences of exercise and newfound knowledge gained from personally-tailored support (Theme 4). Many emphasised the importance of attending supervised exercise sessions for maintaining their motivation for exercise. Honouring pre-arranged appointments (related to supervised exercise), the enjoyment of exercise and feelings of guilt were reported as important facilitators for self-directed exercise. Conversely, the lack of weekly structure when supervision was withdrawn was identified as an important barrier to self-directed exercise. Systematic review evidence shows that level of contact with healthcare professionals, in addition to the use of behaviour change techniques (e.g. goal-setting, self-monitoring) and engaging social support networks are important elements for the maintenance of exercise behaviour change.<sup>27</sup> In this respect, the effectiveness (and cost-effectiveness) of novel approaches to maintaining contact with a knowledgeable health professional (e.g. provision of frequent face-to-face motivational booster sessions; use of mobile and/or internet-based technologies to maintain contact, etc.) is an avenue for further research. Peer-support and camaraderie with other exercising PwMS has been highlighted as another



important facilitator for exercise amongst PwMS in previous research<sup>4, 21</sup> and a greater emphasis on helping PwMS to develop supportive social networks is also warranted.

### **Study limitations**

An important limitation of this study is that participants were recruited from a single centre serving a large catchment living within a few miles of the treating hospital. Hence, views regarding the importance of attending supervised exercise sessions may not be representative of PwMS from rural catchments living further away from appropriate MS-specific exercise classes. It is also possible that participants recruited for this study were generally more motivated to engage in exercise than PwMS from the broader population, as they had all volunteered for the intervention study. Additionally, only participants with mild to moderate MS were involved in this qualitative investigation, and further research is needed to understand the challenges and benefits of exercise participation in PwMS who have higher levels of disability.

### **CONCLUSIONS**

Our participants experienced a transition to inactivity following their MS diagnosis, compounded by a lack of MS-specific exercise advice across clinical and community settings. The individually-tailored support they received from knowledgeable exercise and physical therapy instructors during participation in the program was highly valued. However, the challenge of self-directed exercise and importance of continued motivational support for long-term maintenance was clearly evident in the views of our participants. Further research aimed at developing cost-effective strategies for establishing this provision is warranted.



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**Table 1.** Characteristics of the participants

<b>Characteristics</b>	
<b><i>Focus group participants (N=29)</i></b>	
Females (n)	23 (79%)
Age (y)	48.8 ± 8.2
Years since MS diagnosis	8.8 ± 7.0
EDSS	3.8 (1.0 – 6.0)
<b><i>Interview participants (N=4)</i></b>	
Females (n)	3 (75%)
Age (y)	48.8 ± 7.3
Years since MS diagnosis	9.7 ± 3.5
EDSS	3.0 (1.5 – 6.5)

Age and years since MS diagnosis are presented as mean ± SD. Expanded Disability Status Scale (EDSS) is presented as median (range).

**Table 2.** Semi-structured "a-priori" topic guide used to guide discussions

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**Section 1: Exercise experience before the EXIMS trial**

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*Can you tell us if prior to your diagnosis, whether you took part in exercise?  
How did you find this experience?*

*How has this changed since your diagnosis?*

*Have you been given advice in the past from health professionals regarding exercise?  
Can you tell us who gave you the advice and what the advice was?*

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**Section 2: Exercise experience during the EXIMS trial**

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*Can you tell us about your exercise experiences at the University; was it difficult at the beginning? Did it get any easier? At what point was that?*

*How did you feel during and after the sessions?*

*What kept you coming to the exercise sessions?*

*Did you like the structure of the exercise sessions?*

- *Was it the right amount?*
- *Did you like the mixture of home and supervised exercise?*
- *Did you like the gradual reduction in contact time?*

*Did the intervention, in any way help you to become more active? Can you explain?*

*Have you any suggestions for how the exercise might be improved?*

*Did you notice any improvements/benefits from the exercise? If so what?*

*Did you notice any effects on your symptoms? fatigue, pain, sleep etc.*

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**Section 3: Exercise after the EXIMS trial**

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*Have you remained physically active since completing the study?*

*Did the supervised exercise sessions at SHU provide you with any knowledge/skills that you have been able to put into practice following the trial?*

*Do you feel that you are more physically active now than before the trial and in what way?*

*Has the intervention had any influence on your confidence to exercise?  
Can you give an example?*

*What things stop you from participating in activity/exercise?*

*Is there anything that you feel we could have done during the trial to assist you in remaining more active?*

*What help if any do you feel you need to stay active?*

*Would you recommend exercise to others with MS?*

*Are there any other comments that you would like to make?*

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